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The use of online groups to involve older people in influencing nursing care guidance

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***Abstract**: The drive to involve service users in policy and practice decisions is occurring on an international basis, yet meaningful involvement is not as commonplace as it should be. There are numerous barriers to meaningful involvement of service users, and groupwork offers a potentially empowering approach to helping service users influence the policy and practice decisions that impact their lives. This paper describes a model of service user involvement based on an online communities of practice approach. Twenty-one older people and carers were recruited to take part in a project aimed at influencing the policy and practice of nursing older people on a national level (Scotland). Participants were taught IT skills and worked as an online group to articulate what they thought constituted good nursing care of older people. Together they produced two statements concerning prevention of depression and ensuring adequate nutrition for older people in care. This paper reports on one aspect of a larger evaluation of the project, namely the role of groupwork in the involving model. Content analysis of the groupwork records highlights the importance of groupwork and mutual aid in achieving group goals. The combination of groupwork, service user involvement, and interactive computer technology has much potential.*

***Keywords**: involving service users, online groups for older people, gerontological nursing*

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Introduction

Including service users' voices in the quality improvement efforts and in setting standards for health and social care has become a key policy initiative across Scotland. (NHS Scotland, 2003). This movement for involving service users or consumers is not unique to Scotland for across the UK user involvement is a central element of health and social care policy (Andrews et al, 2004; Local Government Act 2003; Davies & Nolan, 2003; Welsh Assembly Government, 2003; Chambers & Pickerd, 2001; Department of Health, 1999; Raynes, 1998; Audit Commission, 1997; Health Advisory Service, 1997; Barnes & Walker, 1996). Internationally the voice of service users and the general public is seen as essential to planning and providing health services (O'Keffe & Hogg, 1999). Despite the international calls to involve service users, involvement is not as commonplace as it should be (Sumner, 2004).

As will be described later in the paper, there are numerous challenges and barriers to the meaningful involvement of service users in setting policy and practice guidelines. This paper describes the Involving Older People Project which sought to develop a groupwork approach to meaningfully involving older people in the articulation of best nursing practice for older people and to overcoming the barriers and challenges to involvement identified in the international literature. We describe the model of user involvement that was developed and present the research findings concerning the role of groupwork in the model.

Background

The Involving Older People Project was one component of a larger action research study in Scotland known as the Gerontological Nursing Demonstration Project (GNDP). The long term and ongoing intention of the GNDP is the promotion of the principles and implementation of evidence-based gerontological nursing practice within Scotland (http://www.geronurse.com). Here gerontological nurses in practice across Scotland work together in virtual communities of practice to develop clinical care guidance called best practice statements (BPS). Communities of practice are groups whose members share a common practice or professional task and mutually engage to develop a shared

repertoire of resources to improve their practice (Wenger, 1998). Communities of practice function like other groups and the dynamics of mutual aid greatly support the work of the community (Kelly et al, 2005).

Older people were involved in the work of the GNDP and the development of clinical care guidance through conversations with nurses in the community of practice, but it was acknowledged that beneficiaries of the care guidance did not have enough input into the development of best practice statements. A more systematic approach was needed. It was also felt by project staff that the statements were professionally focused and not written in a way that would be useful to older people or their carers. As such, the GNDP team wished to strengthen the voice of users in the development of clinical care guidance and to make guidance more accessible to older people and carers. For older people to become involved in the work of the GNDP in a meaningful way it was felt that the model of user involvement should mirror the nursing community of practice. Hence, the Involving Older People Project was born with the understanding that online groups would need to feature prominently in the developing model. Three discrete areas of literature informed our early work: involving service users, computer use in older people and the nature of online groups.

Literature review

Involving service users

Involvement has been defined along a continuum from bureaucratic to empowerment (Barnes & Walker, 1996) or tokenism and manipulation to empowerment (O'Keefe & Hogg, 1999). Andrews and colleagues (2004) suggest that there are two purposes of involvement. The first is to improve quality of services by making them responsive to needs and preferences of service users, and the second is to expand the capacity of users to participate in decision making about services. The first purpose they identify as consumerist and this approach has been sharply criticized, especially as it is based on a model of market consumers rather than citizenship (e.g., Barnes & Walker, 1996). The second purpose is seen to be a democratic approach and is concerned with developing

skills, capacity building and empowerment so that service users can truly become involved in the services they use.

However one defines user involvement, there is agreement that implementation can be difficult (Cotter et al, 1998). The literature identifies numerous barriers to meaningful involvement of service users in general and older people specifically. These include barriers located within professions as well as those associated with older people. There may be professional attitudes or structures that impede involvement. For example, ageist attitudes may lead professionals to think that older people may not have the capacity to become involved or actively discourage their participation (Dewar, 2005; Sumner, 2004; O'Keefe & Hogg, 1999). Even well-meaning professionals can overlook involving service users, sometimes arising out of time constraints (Davies & Nolan, 2003). Structural barriers can include a host of organisational barriers (Dewer et al, 2004) including a lack of environmental or organisational supports (O'Keefe & Hogg, 1999), power differentials between professionals and service users (Dewar, 2005), and a lack of expertise in involvement of service users (Dewar et al, 2004) and dealing with disparate opinions (O'Keffe & Hogg, 1999). Some barriers are located 'within' older people. For example, older people may internalise ageist stereotypes and believe they do not have the capacity to become involved (Dewar, 2005; Dewar et al, 2004; Sumner, 2004). Additionally, older people may have unrealistic or very low expectations concerning the effectiveness of involvement (Dewar et al, 2004; O'Keffe and Hogg, 1999). Finally, some older people are hard to reach or may be homebound.

A number of principles of effective involvement within an empowering approach have been identified that can help to overcome the barriers identified above. The principles involve partnership, developing structures to facilitate the involvement, and personal development. Dewar (2004) and Barnes and Walker (1999) highlight the importance of building proactive partnerships between professionals and service users over time. Other authors point out the need for the partnership to include choice, equality, and sharing of power (Andrews et al, 2004; Dewar et al, 2004; Davies & Nolan, 2003) as well as the ability for users to define their own criteria and outcomes for involvement (Andrews et al, 2004; Dewar et al, 2004). Partnership also includes partnerships among service users. In fact, some authors point out the need to bring people together who are experiencing similar circumstances (O'Keefe

& Hogg, 1999; Barnes & Walker, 1996). Such collective approaches can prevent tokenism and helps to offset power differentials between service users and professionals.

The principle of partnership must be carried out within organisational infrastructures that support partnerships with service users (O'Keefe & Hogg, 1999; Barnes & Walker, 1996). This involves giving service users access to information and spheres of influence as well as needed support (Andrews et al, 2004), such as transport or financial remuneration (Davies & Nolan, 2003). Involving activities need to fit within the lifestyle of the service users (Davies & Nolan, 2003) and provide ways to reach out and include hard to reach people (Edwards & Roberts, 2000).

Finally effective involvement addresses skill and knowledge development of service users as well as professional staff. For example, several authors point out that work should occur to increase people's abilities, knowledge and skills necessary for real involvement (Sumner, 2004; Davies & Nolan, 2003; Barnes & Walker, 1996). Work should be done to facilitate a transfer of the knowledge and skill to other areas of service users' lives as well.

Though there may be many different approaches, the principles outlined above discuss the importance of collectivity and bringing people together. Although the authors above do not explicitly identify groupwork, their comments suggest that there is an important place for groupwork skills when working to involve service users. Indeed, the use of groupwork provides a powerful method of involving people in policy and service delivery decisions. There is a long history of empowerment, community organising, and capacity building within the groupwork tradition. Gutierrez et al (1995) and Breton (1994), for example, outline the principles of empowerment oriented groupwork practice, and their principles have congruence with and can add to the principles of effective and empowering service user involvement. For example, they include collaborative relationships, shared power, use of small groups and dynamics of mutual aid and teaching specific skills. The methods of service user involvement can benefit from the groupwork knowledge base.

Computer use in older people

Stereotypes persist about older people and their willingness and ability

to embrace new technologies (Richardson et al, 2005; Czaja & Sharit, 1998). However, there is growing evidence from around the globe that older people can and do learn to use computers and incorporate them into their lives for a variety of purposes (e.g., Richardson et al, 2005; Lai et al, 2004; Günther et al, 2003; Ivory, 2003; Kanayama, 2003; Selwyn et al, 2003; Irizarry et al, 2001; Alexy, 2000; Czaja & Sharit, 1998; Sherer, 1997; Hahm & Kikson, 1989). Many benefits to computer use for older people have been identified. These include increased social support, decreased social isolation, improved cognitive functioning, decreased loneliness and boredom, increased capacity for self-care, increased self-confidence and self-image, improved intergenerational relations (Richardson et al, 2005; Lai et al, 2004; Günther et al, 2003; Monnier et al, 2002; Alexy, 2000).

Despite the growing numbers of older people embracing computer technology, significant age differences exist when looking at computer use across current age cohorts. Older people are disproportionately excluded from uptake of computer use (Richardson et al, 2005; Selwyn et al, 2003; Irizarry et al, 2001). In Scotland these age differences appear to be more pronounced than in other western nations. For example, in 2001 only 7% of older adults in Scotland had access to the internet (MacDonald et al, 2001).

The international literature identifies many barriers to computer use for older people. These include: functional limitations as a result of visual, hearing, and mobility changes; financial constraints; cognitive limitations secondary to information retrieval deficits; internalised ageist beliefs about oneself; lack of confidence in technology use; beliefs that e-services are not of benefit; inaccessible web designs; lack of emotional and practical support; age unfriendly trainers; and lack of knowledge and skills (Richardson et al, 2005; National Audit Office, 2003; Quinn et al, 2003; Selwyn et al, 2003; Hendrix, 2000). However, older people are willing to accept and use technology once they recognize it has potential to benefit their lives, and there is available support (Mackie & Wylie, 1988).

Online groups

Much of the literature on online groups is concerned with computer mediated communication in employment based teams or educational settings (e.g., Flanagin et al, 2004; Michinov & Primois, 2004; Chen et

al, 2003; Zornoza et al, 2002; Postmes et al, 2000; Valcke, 1988) and the difference between face-to-face and computer-mediated groups (e.g., Zornoza et al, 2002; Straus & McGrath, 1994). Other literature examines the effect of computer mediated communication on contrived task completion or decision making (e.g. Benbunan-Fich et al, 2002; McLeod et al, 1997; Straus & McGrath, 1994). A growing body of literature also exists related to the helping professions that documents the use of online groups to provide services and information to a wide range of client or patient groups. (See Smokowski et al, (2001) for a good overview).

Though differences do exist between face-to-face and online groups and some tasks appear to be better handled in face-to-face groups, there are many similarities between the two types of groups (McKenna & Green, 2002; Smokowski et al, 2001). In both types of groups members can develop a meaningful and strong group identity through interaction, norms develop over time, intimacy develops, dynamics of mutual aid can be found, and informational and expressive support is provided (Kelly, Lowndes & Tolson, 2005; Meier, 2000; Postmes et al, 2000). Some of the benefits of online groups include ease of attendance, having time to respond, available 24 hours a day, accessibility for stigmatised, isolated or homebound people, and finding others in a similar predicament can be easier (McKenna & Green, 2002; Smokowski et al, 2001; Schopler et al, 1998).

Despite the benefits and similarities, there are numerous challenges for online groups. For example, computer use is new for some parts of society, and some socially disadvantaged populations can be excluded. Others have difficulty writing their thoughts and feelings and find it easier to share face-to-face. Equipment can fail. Confidentiality of communication can easily be breached, it can be difficult to enforce norms, and communication is easily misunderstood without verbal and visual cues. The challenges described above had particular salience for the project presented here, especially when coupled with the obstacles older people face with computer technology in general.

Project design and aims

The overall aims of the Involving Older People Project were to widen access and opportunities for older people and informal carers to participate and learn within a virtual community of practice and to

develop accessible user guides based on the Best Practice Statements (NHSQIS, 2004; NMPDU, 2002). In view of the literature presented above, there were going to be many potential professional, technological, and social barriers to overcome to successfully involve older people in an online community of practice, so an inter-disciplinary approach was needed. To this end, nursing, computing and social work professionals came together to develop and design the Involving Older People Project. The Project was designed around providing accessible technology for older people, teaching older people to use interactive computer technology, and using that technology to work together as an online group to develop service user guides to best nursing care.

Project activities

Participants were initially assessed by a computing professional and a social worker using a semi-structured interview schedule for any functional limitations which could cause difficulty in using a computer. Computers and internet access were provided for all participants. Adaptive equipment such as big key keyboards, special mice, or adaptive software was provided where needed. A user friendly accessible website was designed to facilitate the online group and virtual workspace which included online asynchronous threaded discussion areas, a document repository, online training documents and exercises to build skills and confidence, an e-mail facility, and information about the project.

Computer training began on a one-to-one and on a small group basis. This training was designed to develop skills relevant to using virtual group space and to benefit from interactive computer technology in general. Three face-to-face meetings were held during the project to facilitate the work of the group. There were three different online discussion areas during the life of the project. There were separate areas to discuss the BPS topics (depression and nutrition), and an area called 'Our Computing Diary.' The latter was originally envisaged as an area where people could talk about their experience with computers. It quickly turned into an area where people talked about anything they wanted to discuss – sometimes related to the development of user guides or computer use and sometimes not.

On at least a monthly basis, participants received a visit from a member of the research team to provide IT training and help

troubleshoot computer related difficulties. Other training occurred online, via e-mail and over the phone. In addition, feedback from these interactions was used to further adapt the virtual community or to further adapt the technology.

Model for involving participants

Initially a face-to-face orientation to the project and website was held and participants engaged in discussions of their experiences with health care in general and nutrition and depression in particular. The project then moved on to the online component where in an asynchronous discussion forum participants were asked to: 1.) read and respond to stories concerning nutrition and depression in care home and hospital settings; and 2.) discuss nutrition and depression in care home and hospital settings based on their own experiences or experiences of family and friends. From these online discussions, a facilitator summarized what members seemed to be saying about nutrition and depression. Participants were then asked to discuss the summary to check if it reflected what they were saying and if anything needed to be added or removed. After discussion and debate a final version was developed and again put back to the group for comment. Finally, a group of four participants agreed to design the layout of the brochure. On completion of their work, the brochure was placed online and the rest of the members provided feedback and critique.

Research methods

Research design

The research design for the project was action research influenced by Realistic Evaluation (Pawson & Tilley, 1997), which examines the context and mechanisms required for particular outcomes. The influence of Realistic Evaluation can be seen in our attention to examining in detail the context and mechanisms of the involving methodology under study. Additionally, using this approach to evaluation research allows one to modify the intervention under study when it becomes apparent that something could be done in a better way. This paper reports on only one aspect of the realistic evaluation, namely the use of online groupwork.

Future papers will report on the full evaluation process where the outcomes of interests were computer attitudes, knowledge and skill; overall health, well-being, and social support; and aspirations regarding work, learning, and leisure. Reliable and valid instruments were used to measure these outcomes as well as qualitative interviews at the beginning and end of the project. These included the Computer Attitude Scale (Nickell & Pinto, 1986), the Life Satisfaction Scale (Salmon & Conte, 1998), Kane and Kane's (2000) Perception of Overall Health. The processes studied included computer design, education and training, the involving model, and process of working together as a group. These processes were documented using recorded interviews, field notes and home visit reports, archives of the online group, and video recordings of face-to-face group sessions. This paper reports only on the analysis of the process of working together as an online group and focuses on group processes, content and the skills of the facilitators.

Participants

Participants were recruited using a combination of snowball sampling and advertising in publications for older people. Twenty-one participants enrolled and 17 remained throughout the life of the project. The average age of the 13 women and 8 men was 68.8 with a range from 56 to 94. Most were married (n=13) and 8 were widowed, single or separated. Three participants owned a computer prior to the study. Two of these were a married couple who had bought a computer but were having great difficulty learning to use it. The third person had a very old computer that was upgraded. Nine participants had used a computer prior to the project. Three had taken computer courses at local libraries or community centres, but found the group based tutorials difficult to follow and uninteresting. For the rest computer experience was typically playing a game under a grandchild's supervision or watching an adult child do something. Despite this lack of computer experience, all participants were interested in learning to use a computer, which can be seen as a weakness of the sampling strategy.

Research ethics

The study was reviewed and approved by the university's research

ethics committee. All participants gave their informed consent and all information collected on participants was handled in accordance with the Data Protection Act of 1998. As research staff would be visiting potentially vulnerable older adults, staff were subject to criminal background checks.

The project raised several ethical concerns that the project staff addressed. As participants were not computer savvy and would be going online, a great deal of attention was paid to internet and computer safety to reduce the risk of internet scams, identity theft and computer viruses. In addition, absolute confidentiality could not be guaranteed due to the group and online nature of the project. Group facilitators can never guarantee absolute confidentiality as members may share information from the group with outside parties. All participants were made aware of this limitation and a condition of participation was that group members would respect the confidentiality of other members. In addition, online communication raises confidentiality concerns. Electronic communication can inadvertently be sent to non-group members or be left onscreen for non-members to view. Again, participants were informed of this limitation and instructed in how to prevent such mistakes.

Analysis plan

The findings presented here focus on the process of working together as an online group. Content analysis (Krippendorf, 1980) was the basic tool used for analysing the archives on the online discussion groups. Three broad categories were used for initial data analysis: how the members were working (the process), what the members were working on (the content), and what the facilitators were doing (group facilitator skill). N-Vivo, a qualitative data analysis software package, was used in the analysis of the data. The process of analysis began with identification and coding of issues, content, skills, and group processes in the verbatim transcripts. Coding of the data included frequent reviews and refinement of the coding system. For example, content areas were coded and all the text from each content area was reviewed and compared to the text from other content areas to ensure discrete and conceptually meaningful categories.

Results

Group process

Group processes fell into two large categories: working on socio-emotional tasks and dynamics of mutual aid. Though these two categories are related, working on socio-emotional tasks is in many ways a prerequisite for further dynamics of mutual aid to develop. Mutual aid strengthened the collective nature of the project and assisted members in coming together to form ties and work more productively.

Members working on socio-emotional tasks

Socio-emotional tasks were those things that group members did in order to make personal connections and make the virtual environment a familiar and comfortable social space. Developing connections and making the group safe occurred in many different ways including actively building a bridge or linking to a similar experience or feeling, reaching out for relationship, the use of humour, and social niceties.

For example, members frequently expressed a desire to connect with or develop relationships with other people in the project. Participants would also engage in conversations that could be described as 'social niceties.' These were typically brief conversations that 'grease' social interaction. They help develop relationships and give people a familiar and shared base for discussions. For example, one participant daily placed a 'thought for the day' in a discussion forum. Other social niceties included discussions of the weather, humour, sharing recipes, logging in from Canada to send 'postcard,' etc. As the technology was new and participants were not used to online discussions these attempts to make the virtual space familiar helped participants adjust to the novel communication mode and move into the work of the project.

Dynamics of mutual aid

Shulman (1999) identifies nine dynamics of mutual aid that give groups their helping power. These are sharing data, the dialectical process, entering taboo areas, the 'all in the same boat' phenomena, mutual support, mutual demand, individual problem solving, rehearsal, and the strength-in-numbers phenomenon. Every dynamic was found in the online discussion groups except rehearsal. Several will be highlighted below.

Dialectical process

The dialectical process could be found in a discussion of depression. Participants were responding to a story about depression in a care home when the following exchange occurred:

> *This is my life. Please, it is not easy but it can be done, ignore depression. I put my mind on some other thing and it passes … If she does the same she will come right. I will pray for her. I wish her all the best. I know she will be all right.* Participant 4, Depression Discussion, Section 1, Paragraphs 192-196.

> *Each of us is an individual. Therefore each of us has a unique way of dealing with problems such as depression. While I am happy that you have been able to resolve your own problems successfully, the fact that we are all different means that such self-help does not guarantee success for each person.* Participant 20, Depression Discussion Section 1, Paragraphs 196-200.

> *Participant 4's way of coping by focusing her mind on more positive thoughts is a technique that some people use when they are feeling low. But as Participant 20 says, it may not work if a person is very depressed. She also mentions prayer. I have read some articles recently about the power of religious faith, particularly for older people and how it sustains them in adversity. Does any one else have views on this?* Facilitator, Depression Discussion Section, Paragraphs 217-220.

Other members picked up the discussion and talked about the importance and limitations of the power of positive thinking.

Sharing data

People come to groups with a host of experiences, wisdom, knowledge, and resources. When mutual aid is working, participants freely share these with their peers. In this group, participants became resources for each other. They were able to share data concerning depression, nutrition, hospital care and other information from their vast life experiences. After a short while, they also began to share data about information technology. For example a 76 year old man who had very little computer experience prior to the project shared information with the group about how to use metasearch engines to find information on the internet about depression.

Mutual support

According to Steinberg (2004), mutual support is one of the most

appealing aspects of mutual aid groups. Mutual support provides the glue or a cohesive energy that can sustain the group and its members during difficult times. In this group, participants were very supportive of one another and their quest to learn how to use computers.

> *Hang in there Participant 8 you will also get there So Go Girl* Section 1, Paragraphs 25-26.
>
> *Dear Participant 10 I did the same thing when I tried it myself.* Section 1, Paragraph 36. (Also an example of all in the same boat)
>
> *Good to hear from Participant 10 you done good great first try.* Section 1, Paragraphs 43-44.

Through attending to the socio-emotional tasks and developing the dynamic of mutual aid the participants became a productive group and relational ties were formed. Though there were barriers associated with the use of technology, over time the group was able to function as a group

Content

While looking at group process highlights how members are working together, looking at the content of group interaction gives one a sense of what members are working on. In order to be a productive group, the majority of content should be focused on the group purpose. This was the case in this group. Other than the content focused on socio-emotional tasks, the majority of content fell into one of the following categories: Cleanliness in hospitals (including MRSA), health care in general, ageing, mental health, technology (sharing successes and difficulties), depression and nutrition (responding to stories, describing problems in care, examples of good and bad practice, sharing ideas to improve care, sharing personal stories related to depression).

A few examples illustrate the discussions.

Problems in care

Before participants were able to actively discuss what they thought was best care they spent considerable time discussing examples of bad care or problems in care that they were familiar with.

What a terribly sad story and one I am afraid happens all too often to older people nowadays either in care or at home. I hate to be controversial, but I think … there is now a section of staff that has forgotten the true meaning of care. I think in today's world a lot of basic kindness and common sense has disappeared and no matter how much training and new ideas are put into place without these elements there are always going to be cases like this. I know this is a very simplistic answer and unfortunately how to recruit people with these qualities is going to prove difficult. Depression Discussion, Post Number 206

Reply to thread #206: We must have the most educated nurses re. diplomas and degree honours etc than we have had since the Health Service began in 1947. Yet the bedside manner leaves a lot to be desired, not always the nurses' fault, the increased paper work, staff audits, personal development re staff so how can nursing staff find time to monitor Patients' dietary intake. This also leads to depression as patient is aware nobody is taking on board they are not eating properly. Depression Discussion, Post Number 241

As one of the main goals of the project was to develop service user guides for best care, it was important to get members to describe what they thought was good care. However, it was important to start with the members' concerns. They felt strongly about health care and the NHS and discussing their concerns was energising and engaging for them. These 'negative' or critical discussions were used to describe what the participants felt was important in good care.

MRSA

MRSA and cleanliness in hospitals and care homes was a concern of participants. The topic would come up in discussions relating to nutrition, depression, and in the computing diary.

Newspaper article about hygiene and window cleaning in hospitals. Undercover journalist worked as a window cleaner in a hospital, apparently same tools used time after time in ward after ward, result MRSA! GET THE BASICS RIGHT. There is no point throwing unlimited resources into NHS if simple basic procedures are not correct. Participant 11, Computing Diary, Section 2, Paragraphs 301-305.

You're right Participant 11 about the basics, but do you know what they are? Hand

washing properly for all staff, and patients and visitors. The amount of visitors who just wander onto the wards plonk themselves down on the bed ask to use patients toilets demand access to ward kitchen. We all have to take responsibility for our actions and that includes everyone who is on a ward. Participant 19, Section 2, Paragraphs 310-323.

Though these discussions of cleanliness and MRSA were not directly related to depression or nutrition, members saw the connections between these issues. For example, good nutritional practices for older people, such as having food on the wards for between meals, were discontinued in some health board areas due to concerns for MRSA

Skills of group facilitators

Several professionals were involved with the online groups. A gerontological nurse and a social worker took primary responsibility for facilitating the online group discussion, while the IT professionals would occasionally contribute to group discussions. Transcripts were analysed for the skills used by the facilitators. Skills identified included: encouraging ownership of work, demand for work, providing information or data, reaching for feedback, support, defining structures of work, and reaching for difference. Several of the skills are described below:

Encouraging ownership of work

This skill involved statements or questions that asked members to take increasing ownership of the work and to make sure that the end product really reflected the voices of participants. For example, once participants' comments had been summarised, the facilitators asked questions about how well the summary reflected their comments.

Thank you for your comments on the last draft of the guidance on prevention of depression. I've now added them in and welcome your thoughts on the one below. Please let me have them before Thursday 3rd March so that we can pass them on to the small group who are working on the final layout. Facilitator, Depression, Section 4, Paragraphs 615-618.

Providing information or data

As the group facilitator often has knowledge or information that can be useful to the group, there are times when it is appropriate to share information with the group. There were many times when group members were discussing health care issues and information from the professionals helped move the discussion forward. For example, when responding to a question about who is responsible for an individual resident's overall care, the facilitator shared information:

> *I know that it is good practice in care homes for residents to have a key worker or what's called a named nurse. I would suggest to people that if they have a family member or friend go into a home that it's helpful to find out which people are specifically responsible for their care. Can anyone say something about their dealings with key workers or named nurses who have been assigned to their friend or relative living in a care home?* Facilitator, Depression Discussion, Section 1, Paragraphs 24-30.

The danger of providing information is that if this is done prematurely or too frequently, it can prevent group members from taking ownership or developing their own expertise. It can also shut down communication.

> *An article in the paper this week entitled 'The care that led to despair' went on to say that the policy which was introduced in the 1960s to close mental hospitals and de-institutionalise the patients, named 'care in the community' 'by the politicians' resulted in a reduction of psychiatric beds from 150,000 in 1960 to 35,000 in the mid 1990s. It is now apparently recognised that despite huge cost savings the policy has failed miserably resulting in all forms of misery including several murders.* Participant 9, Depression Discussion, Post 365

> *I can understand why you are concerned about this Participant 9. The papers are always very keen to point out where care in the community is not working. They are not so keen to tell people when it does work. Most older people would like to be able to stay in their own homes, even if they need a lot of help - that is what care in the community is all about. Years ago we had wards full of people who could have been at home if they had just a little bit of help. Some of them were there for their whole life but there was nothing wrong with them. These people were not just older people but people with mental illnesses and people with*

learning disabilities. It is rare now for folk to be taken into hospital because there are a lot of services that help them to remain independent and living at home. It is a shame that the papers make such a big thing about very, very rare events (I don't mean to trivialise murder) but care in the community works well for almost everybody and it has not worked for a tiny few, who, if we let them, may change things for everybody. There are things that need to be improved but I don't think that returning to the old 'asylums' is the way to do it. Facilitator, Depression Discussion, Post 399

To Facilitator,
Your Post No. 399 put an entirely different view to the newspaper article I quoted and if on the whole is successful, I would agree is a much better system. Participant 9, Post 407.

This interaction highlights one of the difficulties in involving service users in policy and service delivery matters. At times service users may be misinformed or hold biases or prejudices that could not be incorporated into policy or practice. Professionals can feel defensive and intervene in a way that shuts down process and involvement, rather than engage the issues and concerns behind the concerns expressed. The professionals involved in the project worked hard to not act defensively, but occasionally, as is shown here, the defensiveness comes through.

Support

Supporting group members is a key groupwork skill. There were many instances of the facilitators providing support for members. Often this came in the form of supporting people through difficulties with technology. At other times it was supporting people in their efforts to discuss topics or in sharing their own personal experiences

I think I have told you all before I have been employed by NHS for thirty years and have loved my job. Over the last three years since the [name of orgnaisation] has taken over I have suffered from depression for the first time, and they have retired me on medical grounds. My GP thinks it's sad after all this time I was so unhappy at work. Participant 19, Section 1, Paragraphs 121-133.

Thank you for your comment and for sharing your own experiences. It seems terrible that people who are expected to support others like yourself are not cared

for by colleagues and the work organisation when they suffer from ill health. Facilitator, Section 3, Paragraphs 603-607.

Oftentimes support was provided around the use of technology. Unlike a face-to-face group where people are used to communicating verbally and in small group settings, communicating via a discussion forum was new and difficult for members. Some were afraid of misspelling words or making typographical errors and appearing stupid. Others found it initially difficult to put their thoughts into a 'permanent record.' Much support and encouragement was needed.

Discussion

Involving service users in policy and service delivery guidelines can be difficult and the international literature identifies many potential barriers to and practice principles for empowering involvement. The approach developed in this project, which relies on groupwork and interactive computer technology, offers a model of involvement that overcomes many of the barriers and uses empowering principles. For example, tokenism and power differentials between professionals and service users are often cited as barriers to real involvement, and skilful groupwork practice is a powerful counter to such barriers. As Doel and Sawdon (1999) point out, groupwork can provide an effective place to experience empowerment and connection with others. Service users outnumbered professionals in this project, and increasingly participants took on greater responsibility and felt free to challenge the professional facilitators. Schwartz (1971) describes this process as a dilution of worker power.

However, it must be noted that despite the efforts of the project team, not all power differentials were equalised. For example, participants were given a choice between working on one of two different best practice statement topics rather than deciding for themselves what particular area of nursing care they wished to address. As such, the professionals set the agenda and had more authority and power. All professional relationships with service users have an inherent power imbalance, however groupwork offers an important approach to sharing authority. In groups, the facilitator's authority is diluted by virtue of being outnumbered, yet groupwork skill is needed to share authority. For example, the function of groupworkers can be seen as a mediator whereby they mediate the inherent tension between the agency's mandate and the needs of group

members until a mutual working agreement is reached (Shulman, 1999). This approach immediately begins to shift power and encourages 'doing with' rather than 'doing to.' One of the ways this power sharing occurred in this group was to negotiate a mutually agreed definition of the work, and participants chose to work on both topic areas. In addition, other areas of interest were discussed as well. This discussion points out the paradox between a genuine wish to involve service users with all the right intentions and the power and authority inherent in the decision to do so. When professionals wish to involve service users in practice and policy decisions, it is they, and not the service users, who set this involving agenda. Involving and empowering strategies must be consciously used and directly addressed with group members.

The literature also identifies professionals' inability or fears of handling idiosyncratic or disparate opinions of service users as a barrier to meaningful involvement. Within the groupwork tradition, such idiosyncratic or disparate opinions are welcomed as they can lead to the dialectical process whereby divergent opinions are explored giving rise to new ideas and solutions (Shulman, 1999). The data show this dynamic of mutual aid working in this online group.

This study also highlights the importance of following principles of user involvement identified in the literature. For example, it is suggested that collective approaches should be used to involve service users. This project was based on groupwork, and, as the data show, mutual aid and other group processes occurred. Hallmarks of empowering involvement include an increase in capacity, a transfer of knowledge and skills, personal development, and increased influence. Through providing the necessary training and support to work together online, these older adults who were previously excluded from the internet age learned IT skills. These skills have been transferred to other areas of their lives. Personal development, another principle of effective involvement, was facilitated by the groupwork based model. The development of IT skills is one such example of personal development. Finally, working together as an online group increased participants' influence on care standards. The companion statements they developed are to be published and distributed across Scotland.

The data show that members were able to work together and focus on group task and content while also working on socio-emotional tasks. Dynamics of mutual aid were evident and supported the work of the

group. These were facilitated through the groupwork skills. The model was effective if judged by output alone. For example, to fulfil the grant requirements the project was required to produce one companion guide to a nursing best practice statement. However, the group decided to produce two statements (NHSQIS, 2005a, 2005b).

When working with service user groups who feel empowered to speak out, it can be difficult for professionals to hear some of the criticisms levelled at them (e.g., the strong critique of the NHS). Defensiveness is a natural human reaction to some of the critique that may occur. However, groupworkers should be used to challenges to their authority as it occurs so regularly in groupwork practice. The practice principles that guide a groupworker's actions when engaging with the challenges to authority (e.g. engaging in discussions of authority, finding ways to share authority) should be part of working with service user groups. There is much to be learned from the critique and it can be used to develop better policy or practice guidelines.

The Involving Older People Project sought to mirror the community of practice approach of the Gerontological Nursing Demonstration Project. Practice is central to the concept of a community of practice, and in the case of the GNDP, nursing older people was the shared practice. The participants in the Involving Older People Project did not have a shared 'professional practice', and some may question whether it was truly a community of *practice*. We defined the practice of the participants as being cared for or caring for an older person. The participants could have been described as a learning community or a virtual community. However, if we were to be truly inclusive, it was important to see them as a community of practice.

The approach described in this paper offers one possibility for user involvement. However, we are cognizant of several issues that may present barriers. Support for information technology and affordability are two major barriers. As the majority of participants had no computing skills prior to the project, significant resources were required to teach and then support them. In addition, personnel resources were required to develop and maintain the accessible website and professional staff time was required to work with the members within the online group. Finally, computer equipment and internet access can be expensive for service users with limited or fixed incomes. Others wishing to use a similar model to involving service users will need to address these resource issues.

Conclusion

Some involving methodologies and groupwork have empowerment as a common goal. As such, blending the agenda for including patient and client voices with groupwork principles makes for a powerful combination. The strength in numbers phenomenon is a well documented benefit of bringing people together to work on a common purpose. Involving methodologies must take into account group dynamics and work to develop the power of the group. Thus the group becomes empowering for members. Interactive computer technology offers a way to bring older people together to work as a group to strengthen their voice and influence policy makers, service providers, and governmental bodies. The combination of groupwork, service user involvement, and interactive computer technology can have synergistic effects, and the combination has much potential. This study supports the belief that older people can come together and work as an online group while learning interactive computer technology and influencing policies that will impact their lives.

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